Experience of physical and vocational rehabilitation amongst individuals with paraplegia

SYNOPSIS SUBMITTED

To

Maharishi Markandeshwar (Deemed to be University)

Mullana, Haryana, India

In partial fulfillment of the requirements for the degree

Doctor of Philosophy

(Physiotherapy)

SUBMITTED

By

AKANKSHA SAXENA

Roll No: 1820747

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Certificate

This is to certify that the PhD thesis synopsis / protocol on, **"Experience of physical and vocational rehabilitation amongst individuals with paraplegia"** has been done by AKANKSHA SAXENA (Reg. No/ Roll no: 20-PhD-020/ 1820747) under our supervision. We are satisfied with the work presented by the candidate towards the partial fulfillment of Doctor of Philosophy (PhD) in Physiotherapy. This is an original work submitted only to Maharishi Markandeshwar (Deemed to be University), Mullana-Ambala, Haryana, and is free of any plagiarism at the time of her submission.

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ABSTRACT

Background: Spinal cord injury is one of the most distressing medical conditions being encountered by today's health care system. In India incidence of Spinal cord injury accounts for 20 per million per years population with 20,000 cases added every year. Rehabilitation services are of utmost importance in empowering these individuals. So there is a need for more qualitative studies through which needs in rehabilitation services can be upgraded.

Aim: To explore the experience of physical and vocational rehabilitation amongst the individuals with paraplegia in India

Methods: In-depth semi-structured interviews will be conducted on 5 to 25 individuals with paraplegia who are community dwellers & are at least six month post-injury. Data will be collected till further no new themes are emerging i.e. till data saturation. Interviews will be audio or video recorded and transcribed verbatim in English. Analysis will be done according to six step process of Interpretative phenomenological analysis using an inductive approach and then entered into Qualitative data analysis tool- QDA miner Lite for analysis.

Discussion: In the present study we anticipate that there are few specialized SCI rehabilitation centre's which work on the concept of a Multidisciplinary team and provide vocational rehabilitation too but there are also some major barriers in our rehabilitation system that endanger their empowerment like scarcity of trained professionals, no SCI specialized centre in rural areas, accessibility is also a major issue, lack of government

funding and policies, lack of awareness and knowledge among individuals with SCI and their caregivers.

Keywords: Experience, Paraplegia, Rehabilitation, Spinal Cord Injury, Qualitative

Chapter 1.0 Introduction

Spinal cord injury is one of the most distressing medical conditions being encountered by today's health care system.[1] In India incidence of Spinal cord injury accounts for 20 per million per years population with 20,000 cases added every year.[2] Worldwide cervical spine injury ranges from 47.2% to 4.8%, thoracic spine injury ranges from 34.6% to 19% whereas lumbar spine injury ranging from 59.4% to 13.3% with developing countries like India having a higher incidence of thoracic & lumbar injuries leading to paraplegia.[3]

Although life expectancy is very good in paraplegics, they still suffer from some common handicap that seriously diminishes their quality of life (e.g., paralysis, spasticity, sensory loss, intractable pain, pressure sores, and urinary and other infections). Appropriate medical and rehabilitation care can prevent these complications and assist the patient in living a long and productive life.[4] Rehabilitation aims to optimize functioning and prevent disability to improve quality of life and well being of the individuals with SCI.[5]

Individuals with paraplegia often experience physical, emotional, relational and economic consequences throughout their life and their rehabilitation is a lifelong process that may go for years and years. So a understanding of how people with paraplegia actually make sense of their rehabilitation is necessary in knowing whether the current arrangement of rehabilitation services are sufficient & relevant enough in helping an individual with paraplegia to return to a productive and happy life.[6]

Currently the focus is mainly on outcome related to function and mobility, using a quantitative or objective assessment to measure the experience of rehabilitation from the individual with paraplegia which results in measuring physical and functional performance between time points A and B and failing to capture the outcomes that are actually valued by the individual that is their subjective perceptions, and how they make sense of their rehabilitation experience.[6] For optimal management of individuals with SCI an in-depth understanding of their experience of rehabilitation services on their activities of daily living and functionality is needed. These type of studies aims to explore “patient perspective” also known as “Consumer perspective” studies.[7] These studies use a Qualitative research design as it is flexible and gives a first-hand detailed description of the experience from the patients itself. Qualitative studies are not frequently used in rehabilitation research.[8]

Very few studies have explored their views on rehabilitation services in their country, one such study done in 2017 explore the expectations of care in India.[9] Although this study take first -hand experience of paraplegics on expectations of care after injury, their unmet/met needs, community reintegration and information regarding their basic skills, focus has not been given on rehabilitation services experience. As this study focussed on all the aspects of care, post-discharge of the patient, focus has not been put on rehabilitation and vocational services in India. So this study aims to explore the experience of rehabilitation of paraplegics in India.

1.1 Need of the study:

1.1.1 Till date there is only one qualitative study regarding care of SCI in India.

1.1.2 As there is a scarcity of qualitative studies in India regarding the experience of rehabilitation, we do not get an answer to why.

1.1.3 So, hence there is a need for a detailed qualitative analysis

1.2 **Aim of the study:**

1.2.1 To explore the experience of physical & vocational rehabilitation amongst the individuals with paraplegia in India

1.3 Study Objectives:

1.3.1 To understand and explore the experience of rehabilitation of the individuals with paraplegia

1.3.2 To identify the facilitators in rehabilitation of individuals with paraplegia

1.3.3 To identify the barriers in empowering individuals with paraplegia

1.3.4 To explore the expectations and experience of vocational rehabilitation of the individuals with paraplegia

Chapter 2.0 Review of Literature

This chapter deals with the review of literature associated with Spinal Cord Injury (SCI), its epidemiology, patho-physiology, etiology, clinical features, assessment and qualitative studies done by far in individuals with SCI.

Spinal cord injuries /SCI's can cause severe impairments of motor, sensory and autonomic functions at and below the injury level by disrupting axonal pathways and segmental spinal cord circuitry both. It can lead to a lifelong loss of function and reduced quality of life (QOL).[1]

2.1 Epidemiology of Spinal Cord Injury

2.1.1 Global

In another review paper published in 2010, comparisons in epidemiology of developed and developing countries is reviewed. Traffic accidents are the major cause in developed countries and falls in developing countries. Most of the developed countries have majority of tetraplegic patients whereas developing countries have higher percentages of paraplegic patients. This variation could be because traffic accidents results in more cervical injury and falls results in lumbar spine injuries.[3]

2.1.2 SAARC countries

In a review on epidemiology of spinal cord injury in SAARC countries done in 2015, worldwide prevalence rate of traumatic SCI was approximately 200 to 1000 per million whereas in India it was found to be 15 to 20 million per million per year population.

Cause of injury in developed countries is road traffic accidents and in India it is falls from height. Gender ratio of male to female is varying in all countries (e.g., 13.5 –India, 1.73- China, 7.55-Pakistan, 0.9- Taiwan). Almost 90% of the spinal trauma patients did not receive any primary health care or first aid; ambulance services were also inadequate in the developing countries which leads to a high mortality rate enroute to the hospital i.e. approximately 90%. They also concluded that people in poor countries experienced limited accessibility to medical services due to lack of transportation, finances, unavailability of etc.[2]

2.1.3 Indian

In a prospective observational study conducted over a period of 9 yrs (from January 2000 to December 2008) in the Spinal Unit of the Department of Physical Medicine and Rehabilitation, in a tertiary care hospital of Jaipur India. They kept track of all the patients admitted in the department over a time period and evaluated their neurological status according to the International Standards for Neurological Classification of Spinal Cord Injury as well as the American Spinal Injury Association Impairment Scale (AIS). For the epidemiological variables, they kept a record of the mechanism of injury, time of arrival in spinal the unit after injury, mode of transport used during transfer of patient, position of patient during transfer, any previous hospitalization history and the type of care provided during admission at other hospitals and any associated injuries were also noted. They found out 2716 cases of SCI where 1400 cases were of cervical SCI and 1316 cases were of thoracolumbar SCI, out of them majority were males (80.8%) and rest were females (19.2%). Seventy one percent of the cases were in the age group of

20-39 years. Ratio of urban: rural was found to be 3.7:1. Majority of the patients were manual labourers and farmers who were uneducated. Epidemiological factors are different in India from western countries, cause of the injury was highest of falls (53%), and then road traffic accidents (28%), fall of heavy object over head (13.7%) and electric shock (4.0%).[9]

2.4 Clinical features

Immediately following the spinal cord injury, a clinical state of flaccid paralysis is seen which includes loss of motor, sensory, autonomic and reflex function at or below the level of injury. This may last for days to several weeks.[10]

The clinical presentation of SCI depends on the level of neurological injury, the amount of damage and preservation of the spinal cord tissue. Motor and sensory impairments depend upon certain features of the lesion like neurological level, incomplete/complete nature of the injury and the symmetry of the lesion. In addition to the motor & sensory dysfunction, SCI can also disrupts autonomic function i.e. outflow of sympathetic and parasympathetic systems. If the injury is in the cervical spinal cord, respiratory function also may get compromised (including hypercapnia, hypoxaemia and poor secretion clearance).

2.5 Classification of SCI

According to the Standards for Neurological Classification, published by the American Spinal Injury Association (AIS impairment scale) founded in 1973 classifies injuries into two types complete and incomplete spinal cord injuries. A complete spinal cord injury is an injury in which there is no conservation of motor, sensory and sacral root function below the level of the injury. A complete injury is given grade A on AIS scale.

Incomplete injuries are those injuries in which there is some degree of maintenance of motor or sensory function below the level of the injury. Incomplete injuries are graded from grades B to E on the AIS scale. The determination of type of injury (complete or incomplete spinal cord injury) is done after the resolution of the spinal shock.[11] In incomplete injuries there are several patterns of neurologic deficit are depicted as Cord syndromes.[10]

The individuals with Spinal cord injury become increasingly independent in their life; still some emotional, relational, physical and psychological consequences remain for the rest of their life. Traditionally we focused on understanding the SCI rehabilitation progress through above listed outcome measures related to function, mobility & independence, using objective or quantitative measures of assessment. These objective outcome measures are effective in assessing physical and functional performance longitudinally from one time period to another but fail to capture the outcomes or views of the individual participant which are actually valued by them. So a deeper understanding of how individuals with SCI make sense of their rehabilitation is required, to know whether the current arrangements of rehabilitation services are sufficient in enabling them to achieve their goals. There is a scarcity of qualitative studies in rehabilitation not only at the global level but also in India.[6]

So to review the qualitative studies done on individuals with SCI, we have grouped the studies on the basis of various major domains as given below.

2.7 Challenges in rehabilitation

In a cross-sectional survey done in Afghanistan, the aim was to describe the challenges in rehabilitating patients with Spinal cord injury (SCI). They used multiple methods in this study like literature search, semi-structured interviews and observation. Interviews were conducted with managers and professional staff of International committee of the Red Cross and also with individuals with SCI and their families. Sixty professional staff and fifty one patients with SCI and their families were interviewed regarding the challenges in rehabilitation of patients with SCI. Literature review found out a incidence of 21 SCI cases per million with acts of violence being the major cause. After analysis of interviews they found out that pressure ulcers and urinary tract infections are the most common complications seen in Afghanistan. There are no medically equipped ambulance services for transportation of patients that results in increased mortality rate. There are no SCI rehabilitation centre's for proper care of individuals with SCI; some facilities are available only in private sector that too in major cities which are apparently inaccessible to rural population. Home visits are common and rehab professionals only have limited exercises to teach the patients. Community integration can only be done when proper post injury care is provided to the patient.[12]

2.8 Barriers in Rehabilitation

A qualitative inquiry was done in Iran three years ago, on healthcare professionals' experiences regarding the barriers in empowering individuals with Spinal cord injury.

They included 11 healthcare professionals from Iran spinal cord injuries research national network who have had at least three years of clinical experience in working for people with SCI. All the participants were from diverse facets of multidisciplinary rehabilitation team i.e. Neurosurgeons, Physiotherapist, Occupational Therapist, Psychologist, Psychiatrist, Sexologist, Social Worker, Nurse & Head of an Empowerment office. Data was collected through a semi-structured interview and analyzed using a content analysis approach. The barriers as perceived by the healthcare professionals are *lack of patient and family education* regarding SCI as explained by the patient: "Injured people and their families do not have enough information about pressure sore and some of them have deep and old pressure sores. Although they have been disabled for many years, they still have urinary problems. They still use the catheter; it means they have not been trained to understand the time to empty their bladder"; *shortage of specialized SCI rehab centres*: "There are so many people with SCI, but there are only few specialized centers for them. There are not enough acute rehabilitation hospitals in our country" and *lack of follow up: "*We had a patient who had fallen off the bed and broken his leg. He did not come for two months and when he showed up, he had sore pain on his hip. He suffered from a knee contracture and in general, his condition was bad. We have no. follow-up systems even by phone for people with SCI and they themselves can be too negligent". Apart from these caregivers and family also have a *wrong attitude towards SCI:* "Some families think that the injured person will sooner or later get better; so there is no need to learn the healthcare activities. They pray to their God everyday instead of doing proper care. I think the denial of disability is a wrong attitude" and neither had they knowledge and

education to curb complications of their patients. *Poor financial condition* and *scarcity of organizations and funding by Government: "*Because of the financial situation, some families cannot make the home suitable for movement of their member with SCI and governmental organizations such as municipality and Welfare Organization might have been able to help them." Or Non-profit organizations accentuate the hindrance in their empowerment. The findings of this study can help the policymakers to provide better social facilities and more support services to people with spinal cord & their families.[13]

A qualitative study done in Mongolia three years back, aimed to explore the views of medical doctors regarding the barriers in rehabilitation services for persons with SCI in Mongolia. They recruited 12 medical doctors with at least 5 yrs of experience in SCI rehabilitation centre and used semi-structured interviews to collect data and inductive thematic analysis was used to analyze the transcripts. The participants listed many barriers that hinder the rehabilitation of SCI individuals. One of the major barriers is the *lack of knowledge and awareness in policymakers:* "The officials in the Ministry of Health do not know or do not understand that rehabilitation is one of the most important health sector in a country. Our government is paying a lot of attention to healthcare for emergency, neurological and cardiovascular diseases. Of course, those sectors are essential as well, but they need to understand all these sectors are directly associated with the rehabilitation sector"; that result in inadequate rehabilitation policies like no healthcare insurance covers the cost of rehabilitation services, public hospitals have *no bed reserved for rehabilitation purposes: "*There is no proper value for rehabilitation services. For instance, a doctor's examinations and advises at all wards have some

charges, but a rehabilitation doctor's examination is free of charge. Our rehabilitation unit is outpatient, so we do not have beds. We provide interventions and treatments for all patients at the bedside in all wards only during their stay" neither have *optimal infrastructure in public hospitals* to support the rehabilitation process(lack of wheelchair, assistive devices, no room for psychologist for taking sessions etc) nor *have enough rehabilitation professionals* to take care of rehabilitation needs of the entire country. Also *rural areas have scarcity of rehabilitation doctors and physiotherapists*. As described by the participants: "rehabilitation professionals are absent. As for personnel, there is no professionals specialized in SCI, so the existing personnel have to provide rehabilitative therapies for all patients, with no differentiation. In the capital city, rehabilitation is improving. Nowadays, secondary and tertiary hospitals have at least one or two rehabilitation doctors and physiotherapists. In rural areas, there are no rehabilitation doctors and physiotherapists". International standards of care cannot be provided to the persons with SCI as there is no concept of interdisciplinary team nor the doctors and rehabilitation professionals have specialized education in the rehabilitation of persons with SCI. There is also low awareness and knowledge among persons with SCI and their caregivers to curb the complications occurring in persons with SCI.[5]

In a qualitative study done in Mongolia last year, the purpose was to identify and explore the environmental barriers as experienced by the individuals with Spinal Cord injury. The data was collected from sixteen individuals with traumatic SCI through semi-structured interviews. The six main environmental barriers perceived are: *poor access to the physical environment, absence of wheelchair friendly transportation, negative*

societal attitudes, inadequate healthcare and rehabilitation services, lack of access to assistive devices and medicines, limited financial resources for healthcare and inaccurate categorization of disabilities in laws. Most of the participants identified physical environment as the major barrier be it *poor access to entrance and exits* of buildings; *restrooms* or *the sidewalks*. One of patient commented as: “I rarely go shopping with my husband or mom. Maybe two times a year [laughed] to big malls like Grand Plaza, which have ramps and lifts. If they are busy, then I cannot go. Of course, I do like to go shopping. I like to choose clothes for myself, but everything is so limited for people like me to go out. I only go to certain places such as the State Department Store and Max Mall because these stores have ramps and lifts”; this barrier is accentuated in students who go to schools where caregivers cannot help them get in & out of the toilet etc like in this case: “our school had many stairs and thresholds. We removed thresholds inside home, but when we go outside the threshold is a pretty big problem for us. You know, we have a culture related to the threshold in Mongolia. For example, when you enter a yurt [Mongolian traditional tent], do not step or sit on the threshold. Mongolian people like to have thresholds inside buildings or home, consequently thresholds are everywhere”. Some participants even told that Mongolians believe that bad luck comes by removing thresholds which make accessibility an issue. Travelling in a absent wheelchair friendly environment is also a barrier for some as a few adapted vehicles are available and the drivers do not have technical preparation for their usage. Private adapted vehicles are few and that too are illegal: “I drove a car without a license for almost two years. Even, if I wanted to take driving courses they do not have that kind of service and the vehicle for us. The law says that if a person is not considered as a

healthy person, they are not allowed to take driving courses. I visited many hospitals to get legal paper saying that I am healthy, only I am a person with disability. But, doctors are afraid that if anything happens, police will take legal actions against them. I also visited many driving courses, asking to get a driving license. But they do not allow". Certain participants experienced discrimination by their family members and also by the employers who think individuals with SCI are not eligible enough to do their jobs. Even there are not adequate skilled professionals & scarcity of assistive devices and medicines, also the welfare schemes provide limited stock: "The social welfare office provides support once in three years for special devices. There is a list of equipment that social welfare gives away for free. We get wheelchairs, crutches, chairs, watches, also sphygmomanometers. Most of the equipment in the list is very not useful for us. I really need transfer devices". The Mongolian law provides accessible transportation facilities to individuals with SCI but these laws are not seriously implemented & enforced.[14]

2.9 Facilitators

In a recent qualitative study done in Iran, the aim was to understand the facilitators for individuals in SCI in regaining independence during transition from hospital to community. They recruited fifteen tetraplegics and paraplegics and collected data through semi-structured interviews. They found four major themes: *social support*, *self-management*, *access to facilities and resources & spiritual and religious beliefs.* The participants believed that adaptation to new life is possible with a positive attitude,

disease acceptance and hoping for the best to counteract the emotional turmoil going on inside them. They also accepted the fact that taking healthy meals, adequate water intake and following proper self-care is the need of the time for them and hence they learn that maintaining self-care themselves makes them more independent and motivated: “I had set an alarm on my watch for every 30 minutes to remind me to change my position so as not to get bed sores, I take my medicines on time, I eat the foods that are good for me, and I try to consume more water and do my exercises regularly at home. They also understood that their participation in activity improves their recovery faster: “Just after the injury, I could not lift my head and they fed me with a straw. As soon as I could raise my hand a little, I tried to slowly eat by myself.… When I could sit up, I tried to do my own things, when I did my own work, I saw that everyone was happy, and I myself enjoyed it more and tried harder”. Participants also increased their knowledge on SCI through books, peers, doctors, internet or anywhere possible which makes them manage their condition in a better way. One major facilitator in achieving independence is social support from their peers, friends, family & doctors: “In the SCI Association, other patients lifted my spirit. They described their experiences and said that they were like me at the beginning, and when they wanted to walk with a walker, their legs trembled, but with effort and practice, they were able to get rid of their wheelchairs, you can walk too if you practice …. Their words made me feel better”. Participants also revealed access to assistive devices, rehab facilities and home modifications had a significant effect on their independence. Home modifications and mobility equipments made them more comfortable & decreased their reliance on others for transfers and their ADL’s. Participants experienced rehabilitation by all various

streams like physiotherapy, Occupational therapy & hydrotherapy also which even made them more physically and emotionally fit: “When I was discharged from the hospital, the doctor prescribed me 20 sessions of physiotherapy, which were done at home. After that, my family took me to the SCI Association in the mornings for occupational therapy. In the evenings, I would go for physiotherapy and swimming. These exercises were very helpful, I was able to gradually achieve relative recovery with a lot of effort and the help of those around me, and do my daily affairs independently …. Using different treatment methods such as occupational therapy, physiotherapy, hydrotherapy all together is very helpful”. They also considered spiritual & religious belief in GOD as a major facilitator in motivating them to go on: “At night, when I wanted to sleep, I was in a lot of pain and I sent so many, then, I calmed down and fell asleep. Although my condition was bad, I prayed while I was lying down. Their prayers are the first thing some people give up when something bad happens to them, but I do not despair and I believe that God will heal me”.[15]

A qualitative study done a few years back aimed to explore the facilitators of post-traumatic growth in patients with Spinal cord injury in Iran. They recruited sixteen patients with Spinal cord injury and collected information by semi-structured in-depth interviews. On analyzing the interview transcripts they found out seven facilitators: *existence of support resources, contact with spinal cord injury associations, spiritual beliefs, positive attitude toward injury, access to proper facilities, enhancement of knowledge and awareness, & active presence in society.* One of the most crucial facilitator is the support after SCI by family members, friends and peers. Apart from the

support from one's family & friends, organizational support is also essential which motivates an individual to train and recover from the injury: "The organization that I worked for prepared me, mentally, to continue my work; they told me that I had to enter my workplace again, and they said that they needed me; therefore, I really felt that, despite my condition, they needed me and wanted me. The organization also created a ramp for me. When I saw these supports, despite all of my problems, my motivation to work in the organization increased". *Contact with Spinal cord injury associations* also an effective facilitator as patients can interact with their peers and understand the severity, complications of the injury and also get tips on how to counteract these issues effectively. *Spiritual beliefs* helps patients in tolerating the difficulties one achieve and helps them in having a *positive attitude towards injury* which makes them understand that this is not the end of their life and life goes on. According to most of the participant's access to proper facilities help them in empowering themselves and makes them independent, this includes assistive devices and rehabilitation team: "New rehabilitation aids are very helpful. Being well-equipped with rehabilitation aids is very important in your success in life. For example, my wheelchair has foam-filled tires, so I can safely move on all surfaces, without having a flat tire. But, if my wheelchair's tires were air-filled, I would be worried, every time I went outside". Last facilitators that participants experienced are the *knowledge enhancement & Social participation* in the society. As per the participants experiences social activity in self-help groups, sports activities divert their mind from the injury and also make them feel still useful for the society and family: "Work, activity, and entertainment, together, can help us, mentally, especially if we do

these things with people who are like us because we have a better understanding of each other, and this mutual understanding can be very helpful".[16]

2.10 Barriers & Facilitators

2.10.1- To social & community participation

In a qualitative study done a few years back in Australia, aim was to explore the barriers and facilitators of social & community participation after SCI. They identified a few barriers like *physical environment* which prevent them from engaging in social activities be it public or private outdoor spaces: "Even the park across the road I either go on the grass which is wet and boggy and whatever or I walk [wheel] around the park basically on the concrete around the park so I'm not enjoying the park"; other major barrier is the *health professionals attitude* and the *attitude of public* in general. One of the participant explained the hindrance in social participation as: "You get stigmatised in hospital as a specific level of injury, not as an individual and you don't know any different back then" or "When you get into crowds, people are not tolerant of us. When everyone is in a hurry in crowds, they walk all over us and if we bump into anyone they get cranky at us. So I wouldn't go to that anymore. Whereas some participants believe that the younger generation of staff is caring and empathetic towards them and not identifies us as disabled. One major facilitator is *technology* especially for those with cervical injuries: "Yeah definitely technology's a huge link to the outside world; having my iPad and then I have my Facebook, therefore I'm linked with people". Transport, availability of car parks

is vital but can be challenging and can act as both a facilitator & a barrier: “If it’s late at night and [having to pull] the wheels across in front of you and getting dirty, put the wheelchair together, get in it, fill the petrol, go inside, take the wheelchair apart, put it back in then drive home, take the wheelchair out, put it back together again. That’s a pain”. *Peer mentor* served as facilitators as participants can relate to them directly: “There’s some things that I had to ask like from females and they put me in contact with other women who are living in the community with spinal cord injuries and that helped me with certain things like makeup and dressing and things like that; things that I couldn’t kind of figure out on my own”. *Health issues* are also serving as a barrier in social participation mental more than physical; “Back then, I mean look I was really depressed, like I was suicidal. . . I think I didn’t really want to go out. . . I was very ashamed of like me and what I looked like, people staring at me. And, so for a while I just needed to get my head around that and I didn’t really want to engage with people for a while until I felt confident.[17]

2.10.2- In sports

In a qualitative study done a decade ago, aim was to explore the perceived benefits & barriers of getting involved in sports by individuals with SCI. They recruited seven athletes with SCI (both tetraplegic and paraplegic) and collected data through semi-structured interviews. Participants reported four main perceived benefits: *socialization, self-worth, physical challenge* and *emotional benefits* whereas barriers were grouped into *organizational*, *medical & emotional*, *lack of information* and *views of others*.

Participants found that through socialization they can learn from others, and can obtain social support & motivation from like-minded disabled people: “It still frustrates me now when I see people of my level of injury and I can’t do what they’re doing. Like getting in and out of my chair by myself and getting in the shower myself. I see people that can do it, so I know it can be done; I’ve just got to try harder. It definitely pushes me harder”. Participants also see their self-worth by proving their physical strength to others, by being independent and hence sports provide them a purpose in life. Many participants also linked sports to maintaining weight, gaining strength, pain relief, improving functional capacity and in reducing incidence of pressure sores etc: “I get a lot [of pain] down my legs and across my groin and it goes up my back as well. It’s like being rubbed with stinging nettles when I’m tired and uncomfortable and every time I move the dreaded spasm kicks-off. When I exercise, I don’t get so many spasms and it changes from a stinging to a tingling. Does that make sense? I don’t know what’s going on, whether it is my brain getting a flood of endorphins from exercise which means I don’t feel so much pain. It really helps with pain management”. Some participants perceive exercise a source of venting anger & provide a form of escape from daily routine. One of the key barrier is the organizational one; travelling to sports area, parking, lack of space, no funding for wheelchair sports etc which frustrates the individuals with SCI even more: “Yeah, I would like to play other teams more often… that would be better. A lot of it [barriers] is funding, a lot of the teams just can’t afford to play anymore. A lot of them have had to fold or they don’t train as often as they should because they can’t afford to. Some even complained another barrier to be cost of equipment or specialized sporting chairs. Others reported complications like urinary tract infections, fatigue and

difficulty resting as perceived barriers that inhibit them from participating in sports: “I had a shoulder injury for a couple of months. It was horrid, horrible. Because it was my shoulder I couldn’t exactly rest but I still did the sport a little bit. When I’m not training, it does get to me sometimes, I drift off into my little world as such, I’m not as bubbly as I am when I’m training. If I can’t train because of injury or illness it gets me quite down”. *Lack of information* and *views of others are* also barriers for individuals with SCI: “Some of them [people], I think say “look at him, getting out and doing things” my family doesn’t think that, you know it’s just like me going to the gym before and going swimming. But people that don’t know me are more patronising and say “you play rugby, how do you manage that?” the study concluded that perceived benefits are more as compared to barriers which can be overcome by proper funding resources, managing complications.[18]

2.11 Transition from SCI rehabilitation unit to home

In an Explorative qualitative study based on interpretive phenomenological analysis done in Denmark in the current year, explored the possibility of transferring knowledge & skills from the Spinal cord rehabilitation unit to home environment and also the structural factors that can influence this transfer. They came across some major transitions like patients faced *external structural barriers* like wheelchair accessibility in their homes and even housing adjustments were rarely successful by municipal institutions. They described the major issue of facing barriers by limited support as: “The

municipal authorities in my are …well, it felt like… whatever I did they kicked me when I was already down. There were problems with my training, and I've been fighting for a Batec [handbike] or a car and haven't gotten either of them. How am I supposed to get back and forth from work?" They were also overburdened by household chores that they cannot prepare healthy meals and even the exercise at home were not supervised and did not support cardiovascular training or their goals ("Now that I'm back home, there are so many things I have to deal with. My kitchen is hopeless, my front door needs a ramp, I have to sell my car and then… job, girlfriend, and well… sports! I feel stressed, and I need to go to the doctor because I have high blood pressure"). Patients felt guilty owing to increased dependency on their caregivers at home: "Everything has changed. We used to help each other with household tasks. I feel guilty about that I just sit here, and she's [wife] been at work all day, and then has to vacuum, cook, and do the laundry as well … but without my wife, my everyday life would be completely unmanageable". Patients with SCI felt alone due to lack of peer support which they had in SCI unit and also their personal relationships changed with time. Another major theme identified is the *balancing loss and acceptance* by participants; on the one hand participants experience loss ("I don't think my children deserve it… I just want to go for a walk with them or pick them up from daycare. I've such a bad conscience when I just turn on the TV, but it's because you don't have the same energy as before. I don't feel like I'm teaching them anything. I'm not showing them how to live life") on the other hand some participants accept the current situation & are grateful to be alive: "I knew I would never stand on my legs again, but I thought… does it matter? I can breathe, I can hug my family, I can say that I love them, and I can still play my PlayStation.[19]

2.11 Vocational Rehabilitation

A qualitative study done in Australia a few years back, explored the opinions and perceptions of health professionals regarding in-patient vocational rehabilitation. They included 25 medical staffs from three Spinal Cord Injury Units of Australia through focus group discussions which was later analyzed thematically. The staff found InVoc rehabilitation program a better opportunity to reach out to all the patients with SCI as these sessions of InVoc are *flexible* that can be rescheduled according to the timetable of the patients. Due to the *coordinators working in the wards* and the *staff communication*, InVoc can help a large population of SCI survivors in the crucial time so that they can return to their work or education. Also timeliness of the program, is a major advantage to the participants as given in their own words: "I think based in this setting, in the rehab setting, I don't think that it is too early … it fits in well with the model of service here in regards to goal planning and getting the clients to then think about, "well I'm going to be returning back to work, what am I going to need to do in order to get back to work?". Overall staffs perceive InVoc as essential to the patients: … the whole fundamental idea of rehab is to get people back living their lives. So without work, we spend most of our day at work. That is part of life. It's a necessity; it's such a valuable thing." According to the participants, this program address to the gap in the patient care and was perceived as appropriate by the patients as well.[20]

In a qualitative study done a few years back in Sydney (Australia), the aim was to examine the perspective of the participants of a vocational rehabilitation program

conducted over a 2 year period. The participant's feedback of the experience of the integrated vocational rehabilitation services in hospital setting was examined through semi-structured interviews. They recruited thirteen participants who completed their vocational rehabilitation on time. Out of 13, 12 participants were employed at the time of interview. Two major themes emerged from the data analysis: *timeliness* and *critical elements of the program.* Most of the participants found the vocational rehab program timing appropriate: "Not – not particularly. I didn't feel that was a big issue. It was probably – probably the right timing. I was approached, probably I think, maybe first two weeks, I – I think. No I didn't – didn't feel like it was too early, but I think that was the – the trial whether or not having early intervention was a – was a – had any impact" whereas some found it too early for them as they were trying to get physically better rather than thinking of the career: "I think it was too soon like I say, I'm having trouble just moving around. I can't see me doing, returning to work and doing anything useful." Most of the participants perceive that program creates a positive expectation & motivation in their minds: "the earlier the better because the more time that you leave it, the less likely I probably would've been to, to get interested in it…" and "…helped me boost my confidence even more to go back…" Some other themes emerged from the analysis like *hope, a sense of direction* and *advocacy & support.* Some comments from the patient are "put in better frame of mind…clearer future…some solid goals we can work towards…big part to play in managing someone's mental health" and "*the really helpful things were providing me with details of, you know, the various support services at uni and – and that, you know, studying was a possibility*". Participants also referred the service providers as their 'referees' who in a multidisciplinary team provides support

& motivation: "*And, being an unexpected situation, you have to deal with the emotion and to deal – and, try to organize your life from one day to the other in a totally different way, so, it was for me, in my personal point of view, to have [staff name] there and she was so reassuring and she was so caring and so pleasant, and there to tell me, okay, I – I'm not alone".* They also specified certain areas that need improvements like *better communication* and *overload of information* like given in this comment from patient: "in acute it was very rushed and you know, lots of time commitments, so I think I – when I saw them there was – they were popping in and out and sometimes had information for You. But I can definitely see how having lots of competing interests with lots of different health professionals doesn't help and not having really the – the idea of what was happening or what was going on, didn't really help".[21]

A qualitative study using a mixed method approach was done a few years back with a purpose to understand the experience and pathway of individuals with SCI in relation to employment. They recruited approximately 30 participants and grouped them in A, B & C groups with Stable and durable employment; Unstable employment and into Without employment groups respectively. Data was collected through semi-structured interviews asking questions about the experience of seeking, gaining & maintaining employment. After data analysis they found out that people with stable employment were relatively younger, were employed before injury and had a insurance cover whereas in unstable employment group were not in stable jobs due to their co-morbidities like pain, ulcers etc and more than half of the participants received insurance cover money. In Without employment group participants were mostly

tetraplegics and require assistance in their daily chores. Participants in group A were focused on achieving & maintaining employment to be financially independent and give a purpose to their life: “had so many people tell me like just focus on your disability and learn about that first . . . I already knew what the deal was . . . it’s like well a job’s not going to take away 24 hours of your day, you can still research, learn your disability”. The participants identified a *supportive employer* as a major facilitator in regaining employment post-injury. Participants in Group B & C had a strong motivation to work but some had other liabilities to cater to like in this case: “I’m a full time parent. So all my work needs to fit in within school hours usually you know*”* or where pre-injury workplace is not wheelchair friendly. Group A participants had a good *understanding of their rights* and were aware of all rules & regulations while Group B participants did not had comprehensive knowledge of insurance etc. Most of the participants were motivated to have jobs be it a shift in job roles or at another workplace: “Yeah I want to do something useful and productive but I just don’t know what to do and now I’ve figured out what I want to do so it’s good . . it’s about sort of meeting people and spending time with people, I don’t want to sit at home by myself all day and only ever see [partner], you know you need to have relationships with other people and I’m missing that, I’ve been missing that for too long it’s huge”. Many participants found unsupportive *social support* as a hindrance in maintaining employment: “the main problem is its accessing care. . . Luckily I’ve got just enough but I had to fight for ages, and ages to get enough care hours to live independently”. Some participants experience adequate *social support* from families, peers etc that help them be more independent and motivated like I this case: “playing rugby with the boys has taught me a lot. . . works, plays rugby, has a

family. . . there's other blokes out there that do it. . . that really motivates me even more". Through this study a understanding and insight into employment pathways is gained through which policy makers can take help in planning laws, vocational skills etc.[22]

A qualitative study done a few years back in Switzerland examined the long-term employment pathways experienced by individuals with SCI. they collected data through narrative interviews with individuals who completed vocational rehabilitation course during their rehabilitation process. They conducted fifteen individuals with SCI and on data analysis found out four pathways: Pathway of no paid work, Pathway of retraining, Pathway of job adaptation and Pathway of continuing work. The participants in the pathway of no paid work described few issues in maintaining employment like *inaccessible workplace*, *complicated relationship with pre-SCI employer*, *health complications* or are *trapped in a pre-SCI identity*. Some participants described their inaccessible workplace as: "You see, also there [the building], I would have no chance to work there with a wheelchair. It is the toilets, a huge problem. Always too small*"* or some are stuck in old job identity and are not willing to change & adapt like in this case: "I did not see myself in any job. I always saw a table in front of me, what else could I possibly do? You can't carry around things, but for me working is carrying around things and not sitting in front of a keyboard. That's nothing". Participants also came across that employers do not consider them as potential employees and they are frustrated getting rejected every time. The participants in pathway of retraining could not go back to their pre-SCI job as it is wheelchair inaccessible and have to rely on vocational

courses which they cannot complete due to health complications. Participants perceived vocational rehab as their new employment identity and are happy to be recognized in it: “somehow fascinated me. I could imagine doing that, having a job which has to do with my former job. In the third pathway of job adaptation participants had a close relationship with their previous employer and they managed to provide a job suitable to them post-SCI: “think that would have been bad i.e. doing nothing. I don’t know what I would have done. Probably I would have done something else. Necessity is the mother of innovation, but I would have started something, that’s for sure*”.* Finally in the pathway of continuing work, they received support from their pre-SCI employer: “No matter how, where and when, she is coming back to our company”.[23]

2.12 Global meaning in rehabilitation

A qualitative study was done to explore whether aspects of global meaning like fundamental beliefs, life goals, core values, worldview, identity and inner posture are associated with processes and outcomes of rehabilitation. The study was conducted on people with SCI living in community receiving outpatient rehabilitation. They recruited 16 people with SCI and conducted semi-structured interviews and observations to collect data. They found out that rehabilitation outcomes that are affected by global meaning were *physical functioning*, *emotional functioning, social functioning and subjective sense of meaning*. Participants perceived help in regulating *their emotion, making decisions, managing stress* and also *get motivated by the core values of commitment, relationships, positivism and worldview of seeing things* in a positive and whole manner.

Some participants get help in making decisions like in this case: “Go on. That’s the only thing, that’s what I want, yes. Well, it was a problem, for those people, every day, they were just waiting to go to sleep, and eventually die. They just wanted to die. They didn’t want to go on, but they had to. I thought that was terrible. Here it is different. I like it here; this is much better. I had to do it, to move here.”Participant’s worldview helped them in regulating their emotions like this: “When we are sad, when things are heavy, my wife and I cry together, but then I say: ‘stop, I have to go on’. And then I go on again. You just have to go on. Everything goes on, back to the source. And then it starts again. One would be stupid to not go on, wouldn’t one? Of course you go on, you just do” and in handling stress as in this: “In two years, after rehabilitation, which boss is waiting for me, 44 years old and having SCI? No, I can forget that. [People ask:] does it not gnaw at you? I say: no. No. I won’t allow it to gnaw at me. I know that I am a strong person. I know that I am sporty. I have perseverance.” Global meaning also influenced rehabilitation outcomes like physical, emotional & social functioning by having faith in God that makes them to never give up. Spirituality also provides participants with a subjective sense of meaning. They concluded that all aspects of global meaning were positively associated with various processes and outcomes of rehabilitation.[24]

2.17 Experience of rehabilitation

In another Qualitative phenomenological study done half a decade before on tetraplegics of New Zealand aims to explore the experience of rehabilitation from the perspective of tetraplegics. They included four tetraplegics of traumatic spinal injury

level from C1/C2 to C6/C7 and with Asia Impairment level of A to C. The study conducted semi-structured interviews and used Interpretive Phenomenological Analysis (IPA) approach to gather the subjective perception of all the participants. They found out three major domains- *Acquiring information*, *Regaining control and Restoring a Sense of personal narrative.* The participants had little knowledge on SCI and wanted to know each and everything about SCI, they also identified staff as key distributors of information. One of the participants described " there was excellent information and they gave me pamphlets and explained to me about the, the pamphlets for like bladder, or bowels or um, anything to do with any problems I'm going to ah, I think I'll experience after I left there, they were more willing to explain things um, about my, my body and that and ah, like ah, you know they emphasized to me about um doing um, pressure relief all the time, you know", they went on describing that delivery style of staff can create both a positive and negative environment. Participants also explained that peers were a great source of acquiring information as well as motivation-" to get first-hand information from another tetra or para, you know it's ah, very valuable . . . you're learning everyday all, you know, you never stop learning . . . picking up ideas from other, other wheelchair patients . . . they gave me a lot of information to ah, to look forward to what's going to happen out there . . . they give me ah, idea to understand, you know. . . life in a chair". A key factor to regaining control by participants lie in the feeling of inclusiveness in the decision making process "you're on tea tonight, and it's like what do you mean? and it's like you're cooking . . . they pretty much um, just help you, you know, um . . . learn . . show you like what it's going to be like at home . . . at the end of the day I've gotta make my own decisions". Also the participants faced

problems from switching to rehab unit to home environment as the spinal units were a safe wheelchair friendly environment as described by one of them: “you start to have nervousness about leaving the whole environment . . . because you’ve been cocooned in this environment for many, many months as a tetra . . . it’s a big jump” They found out that participants considered SCI as a biological disruption to their life that limited their functional capabilities and disrupted their “Life’s biography”. Participants rely on good staff for their physical, mental as well as emotional stability. Rehabilitation allow the participants to imagine a future where they can regain a control over their life and can have a healthy, happy relationship with their family, friends etc.[6]

In another multi-centric qualitative study done in United Kingdom a one and half decade before, the objective was to develop the knowledge base regarding women’s experience of SCI rehabilitation. They recruited 10 women with mean age of 50 yrs from four SCI rehabilitation centers’ (both quadriplegic & paraplegics) and of both traumatic and non-traumatic SCI. They collected data through in-depth interviews and analyzed according to Grounded theory approach. They identified central theme of *vulnerability* that includes *feeling insecure, powerless* and inferior after data analysis. They also found out that *lack of privacy*, *lack of gender sensitivity* by staff and *disrespectful attitude* towards the patient by the staff also amplified the vulnerability. The participants explained unavailability, poor *communication by staff*, no *involvement in decision making* were also some major factors that enhanced their vulnerability. Some of them go on in describing *violations of privacy* by other staff members and also no private space for female SCI patients: “The way it is is horrible there is no showers for ladies &

no toilets for the ladies….you just have to share a shower, there's a man in the next one, there's nothing you can do about that, that is not nice, that is one thing I did not find comfortable at all". Some participants explained their positive experience of living in a private ward with some of their peers and the attitude of OT & PT staff in reducing that feeling of being vulnerable all the time: "sort of the Occupational Therapists, it's all hands on and they'll keep you motivated and they'll sort of tell you that you're improving, which makes you feel better, and the same with the Physio's you know they'll sort of jog you forwards, give you the confidence and encouragement to make you go on". They concluded from this study that SCI rehabilitation environment and interactions can have either a positive or a negative impact on women SCI survivors and this feeling of vulnerability by women individuals with SCI can be curbed by a receiving support and encouragement from staff, by avoidance of mixed sex wards, by enhancing privacy in wards and bathrooms and by collaborative goal planning programmes.[25]

In an explorative qualitative study, done a decade ago in Pretoria, which aimed at exploring the views of patients regarding their rehabilitation while in hospital. They recruited twelve SCI patients and collected their feedback through semi-structured interviews. The study found out a variety of psycho-emotional issues related to experience of rehabilitation. Some of the positive issues are the *emotions,* some participants are accepting their fate ("You can either sit and cry, or do something with your life") while others are disheartened by the injury ("Before the injury, I had plans to marry...all is lost... hopeless*").* *A sense of loss* and *non-acceptance* can discourage participants in working hard and losing hope. Another factor *family support* serve as a

positive emotion in empowering these individuals: “My wife is helping a lot. She visits me often, and that helps*”.* One of the most negative experience of the participants is that they were *not allowed a say in their goal-planning* by their therapists which makes them dissatisfied by the rehabilitation: “They know what I need. What can I say? I just do what they tell me”. Therapists and patients should be in sync or trusting each other in order to achieve the desired goal. The last negative emotion is the *insight*, patients are not aware of their condition, its complications, prognosis etc which often leads to dissatisfaction, anger and decrease in motivation level: “I don’t know, I am not a doctor. They told me something about the spinal cord...I don’t know*”.* They concluded that in future while planning a rehabilitation plan for a individual with SCI, these points should be kept in mind.[26]

In a meta-synthesis of qualitative researches done about more than a decade ago, the objective was to identify, compare all the published qualitative evidences on experience of in-patient rehabilitation following Spinal cord injury. Out of the 64 papers and 4 books, 7 papers were identified out of which only 2 papers explore patient’s perspectives of experience following SCI. Participants labelled staff into categories like “caring” who go an extra mile in rehabilitating them, “who were valued”- who involve them in decision making & goal planning, “bossy” who were arrogant & were least concerned with their progress and did not involve them in goal planning. Apart from the bossy type of staff, most of them were assigned staff who had no interaction with the patients or are not following any evidence based treatment at all. Peers had a great role in encouraging and motivating the patients, patients were able to identify them as their

own and discussed their problems and doubts with them. Some patients also compared rehabilitation centres with jail that had some fixed schedule and were least concerned with their needs and were too bureaucratic: “I’m sick and tired of being pushed around and having to live with the rules in this f…ing place’. *Staff inflexibility* and *unwavering adherence to rules and regulations* that governed every dimension of their lives were perceived to demonstrate an ignorance of what it was like ‘to live here 24 hours a day.”Another concern that was found out in the review was the content of rehabilitation was standardized not tailor-made for each and every patient: “a bad day is when you have time to kill…Since I’ve been in this place; I watch a hell of a lot of TV”. Rehabilitation programs fail to transfer the skills taught in rehabilitation centre’s to home or work environment, and hence fail to prepare clients to meet the needs of the real world: “Nothing against your profession (physiotherapy) but you people know all about what it is like to go through (SCI)”. This meta-synthesis bring into light many barriers related to rehabilitation that can be counteracted in future for a better experience of rehabilitation for individuals with SCI.[27]

In a qualitative study done in India a few years back, the aim was to understand expectations of persons with paraplegia regarding their care. They included community dwelling complete traumatic paraplegic adults who have had at least 6 months post injury duration. They recruited 24 participants and included them into focus groups of 2 to 4 participants and collected data through interviews conducted on Zoom app. Topics included in the interview were met/unmet needs, post-discharge care, information on their basic skills, daily tasks, community integration and also their suggestions to

improve the standards of care. After data analysis they came to the conclusion that due to *lack of awareness:* “I had lots of expectations but they have not been fulfilled”*, knowledge and education* their *expectations of care were unrealistic: “*Doctors did not tell me about rehabilitation whether I should do it or not. They did not tell how to care for ourselves. They should atleast tell us what it is”. One of the participants explained his anger as: “We used to have meeting with doctors and staff about our improvement and treatment goal. I used to tell them to make me stand on my feet. I feel that they have done cheating”. They also identified some major barriers like *lack of specialized SCI centre’s in rural areas: “*“Life gets spoilt for the ones who stay in a village”*, environment is not wheelchair friendly:* ‘If we have to go to a bank, we get stairs. There are no ramps. Even in railway stations, there are stairs, and no ramps. It’s a big problem*,* Government has *no policies and funding:* “Government should intervene and improve the infrastructures” for neither for their rehabilitation nor for employment of individuals with SCI. Health professionals and patient education post-discharge is crucial in empowering the individuals with SCI in India.[28]

Rehabilitation outcome usually results from patients attitude, thoughts & motivation of the whole rehabilitation process as a whole, studies that use a qualitative design could become a useful tool in assessing rehabilitation outcomes and improving the scenario of rehabilitation process. Till now, India has only one qualitative study done on individuals with Spinal cord injury, so there is a need for more studies that go deep in participant’s perception and beliefs and thus can bring about the required changes in rehabilitation.

Chapter 3.0 Methodology

3.1 Study design: A qualitative phenomenological Multi-centric study

3.2 Sampling Design: Non-Probability sampling

3.3 Sampling technique: Purposive sampling and Snowball sampling will both be used to select the sample as qualitative researches usually requires more than one sampling strategy (Sandelowski et al, 1992). The sampling strategy will develop during the project, so might start with purposive sampling first, and then go on to following up leads given by the participants who can provide more knowledge on the topic.[29]

3.4 Ethical approval: was obtained from Institutional ethical committee of the MMIMSR with a number-MMDU-IEC/2154. The study is registered on ctri.gov.in with a trial no: NCT05267223.

3.5 Sample size: 5 to 25 participants (According to Polkinghorne, 1989) till data saturation i.e. once no new themes or codes are emerging.[30] Studies have been done with a diverse number of sample sizes of 4[6], 10[25], 12[26], 20[28] etc. However, we aim to collect minimum of 5 samples (n=5) and continue till data saturation.

3.6 Participant Selection Criteria:

Inclusion Criteria	Exclusion criteria
Traumatic & Non-Traumatic individuals with paraplegia	Communication problems[24]
Both male & female above 18 yrs of age	Psychiatric problems or co morbidities like head injury [24]

Time since injury of minimum 6 months[28]	
Community dwelling paraplegics[28]	

3.7 Data collection: Data will be collected by in-depth face to face, semi- structured interviews. Interview questions were developed by the primary researcher AS and guided by sufficient search of the literature and multiple discussions by all three researchers (AS, AJS & MS). The questions followed Miller and Crabtree's recommendations for in-depth interviews.[31]

3.8 Preparation of Interview guide

The interview guide designing followed the two-step method described by Stein and Armstrong et al. It is a two-step process: Step 1: **Instrument design and Construction**- was done by thorough literature review from various databases like Scopus and PubMed, to identify the major domains and items to be added in those domains. The first author AS reviewed the literature and identified main domains and then after numerous discussions between all three authors AS, AJS and MS, three main domains were found: *General experience and expectations from rehabilitation care, Physical rehabilitation experience/ barriers/facilitators and Vocational rehabilitation* which consisted of 27 items or questions. Step 2: **Content validity** measures how well the items correspond and reflect the domain for which it is intended to measure. This study utilized a non-face to face method to check content validity by experts.[32] The expert panel consisted of a multidisciplinary team consisting of physiotherapists, occupational therapists, neurologists and neurosurgeons all having experience of

working with individuals with SCI. Ninety four experts were chosen for a panel for content validation and were send the Interview guide through Google forms via Gmails, Whatsapp groups and through individual messages. The critical appraisal of each item was done on a 4-point Likert scale where 1= not relevant and 4= very relevant to the domain [13]. Nine experts with an average experience of 14 years accepted the request and filled the form along with their suggestions. Modifications were made accordingly and a final draft was obtained of the interview guide which included 15 questions with scale Content validity Index (S-CVI) of 0.897 by Average method and the Item -level Content validity Index (I-CVI) ranges from 0.78 to 1 of all 15 questions.(Appendix) Later a translation will also be done in Hindi by a professional translator.

3.9 Procedure

The interviews will be carried out in a quiet room and at the participants preferred time in the rehabilitation centre itself. If the participants are comfortable with their rehabilitation therapist or any caregiver, they will be allowed to be in the same room the interview is being carried out. All the interviews will be conducted by the primary researcher AS, who has a PG degree in rehabilitation and is currently pursuing her Doctoral in rehabilitation from a recognized rehabilitation institute. The researcher will introduce herself first and will try to establish a connection with the participants first by making them feel comfortable and then will ask few questions on their demographics and then finally will move on to the main research questions. Topics for interview guide will be regarding their general experience and expectations from both physical and vocational rehabilitation care, their perceived facilitators and barriers regarding their empowerment and regarding the help rehabilitation provided in their daily activities and

in community and social integration and at last their suggestions to improve the rehabilitation care in India. Certain probes will be used to facilitate the interview process like please give an example of the same, can you elaborate this point a little, etc. Each interview will last for nearly 30-45 minutes and complete anonymity will be maintained while recording and interviewing. All the interviews will be audio or video recorded and also manual notes will be prepared for their analysis after the interview is conducted. Data collection will stop once data saturation is achieved i.e. once no new themes or codes are emerging.

3.10 Data analysis

Data will be analyzed thematically using an inductive approach as the study is aimed at understanding and exploring the individuals' experience rather than confirm a preconceived theory. Data will then be entered into a software program for qualitative data analysis and research, QDA Miner lite version 2.0.8 developed by Provalis Research (available from www.provalisresearch.com). Transcripts will be analyzed using 5- step approach of Interpretative phenomenological analysis by the primary researcher (AS) and further confirmed at each and every step by the other researchers (AJS and MS). The first author will read and re-read the transcripts multiple times of each interview to understand and familiarize with the data, will generate initial themes and find out emerging relationships between those themes. Finally the researchers will cluster these themes and will summarize and collate major themes.

3.11 Research Rigor

Trusworthiness of the research is the confidence in data, interpretation and methods used by the researcher in maintaining validity and reliability of the data. According to Lincoln and Guba trustworthiness or quality of the study can be maintained by Credibility, Transferability, Dependability and Confirmability.[33]

3.11.1 Credibility

Credibility is the internal validity of the qualitative researches which seek to ensure that the study measures what was actually intended to check. Member checking and method triangulation will be used for maintaining credibility and generalisability of the data. In member checking, the transcribed transcript with their major summarized findings will be verified by the participants to ensure the same meaning has been written which they intended to transfer. If they will suggest any modifications, reframing of the summarized findings will be done accordingly. To maintain credibility of the data, method triangulation will be used to collect data, where we will utilize observation, semi-structured interviews and diary method.[33,34]

3.11.2 Transferability

For ensuring transferability of the data, purposive sampling will be used to collect sample. Also a Thick description of the phenomenon under scruting will be kept so that not only the behavior and experiences will be taken into account but also the context, participant characteristics, data source, data collection techniques and period will be noted so that the actual situation can be found out. In addition to the above, comparison with other studies and replication of the results across multiple settings can be done.

3.11.3 Dependability

Dependability is the reliability of qualitative study that means if the work is repeated in same context with same methods, same results will be obtained. This is achieved by Audit trail which allows any researcher or auditor from outside the study having experience in qualitative researches or in spinal cord injury can trace the steps in the process of the research, its findings and conclusion on completion of the study to confirm the findings obtained. This includes all the steps from rationale of the study, sampling criteria, interview questions to obtaining results and conclusion of the study.[33]

3.11.4 Confirmability

Confirmability is concerned with establishing the fact that the results and findings are not made up by the researcher according to his or her own prior conceptions and preferences. Strategies such as Audit Trail, Data triangulation and Reflexivity can be done to ensure confirmability. Reflexivity can be ensured by keeping a Diary by the primary researcher to jot down all the preconceptions, assumptions and feelings and how they can affect the results or findings of the study. In this study with the involvement of multiple researchers, reflexivity can be maintained.[35]

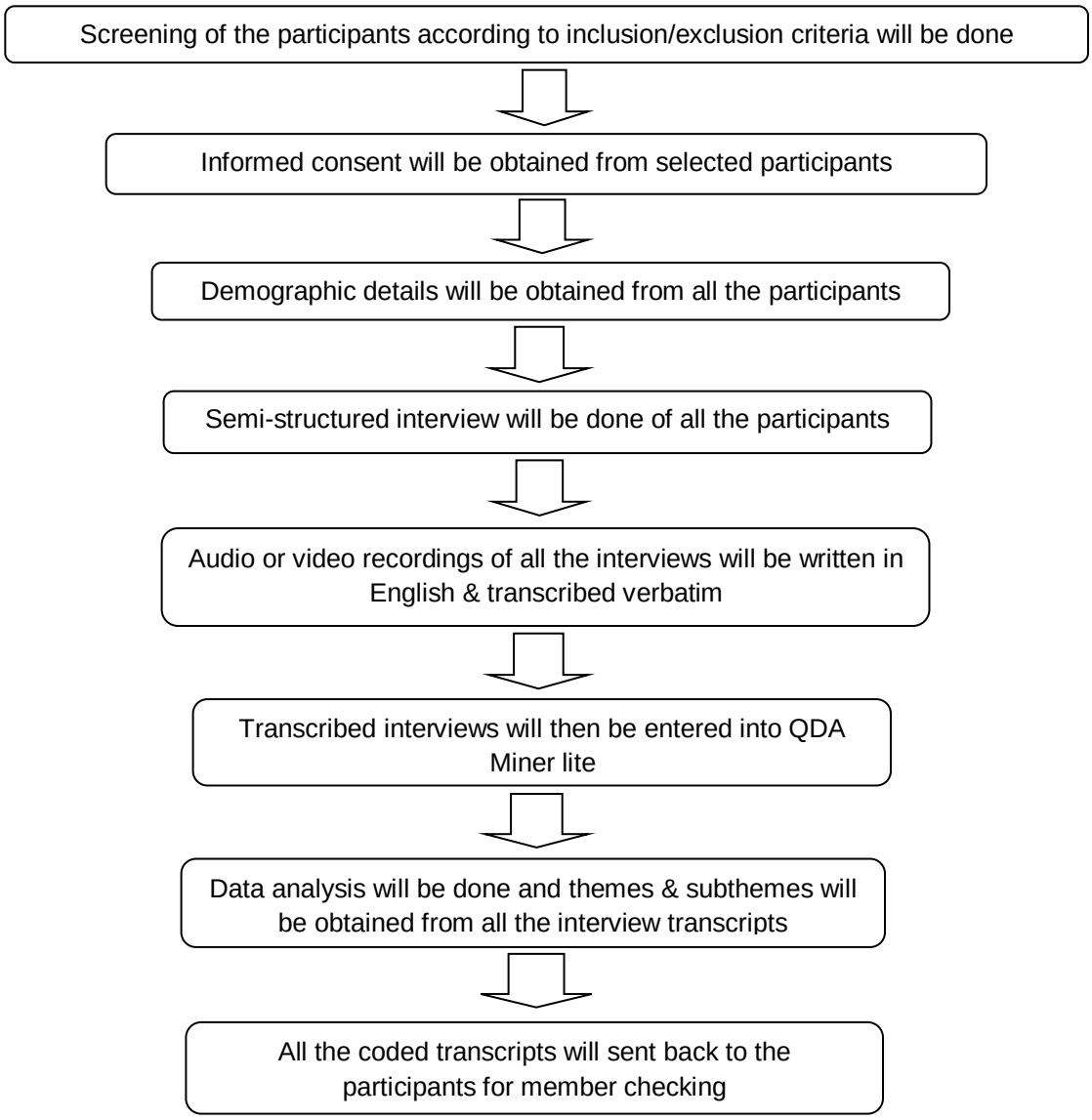
Screening of the participants according to inclusion/exclusion criteria will be done
Informed consent will be obtained from selected participants
Demographic details will be obtained from all the participants
Semi-structured interview will be done of all the participants
Audio or video recordings of all the interviews will be written in English & transcribed verbatim
Transcribed interviews will then be entered into QDA Miner lite
Data analysis will be done and themes & subthemes will be obtained from all the interview transcripts
All the coded transcripts will sent back to the participants for member checking

Figure: 3.1 Flow diagram of the study

Chapter 4.0 Results

Results will be depicted in form of tables and Word clouds. Word clouds will be formed through QDA miner Lite software to localize the main themes and semantic codes that will emerge from each transcript.

Figure 4.1: Demo word cloud of the study

Chapter 5.0 Discussion

In the present qualitative study we anticipate to explore the experience of rehabilitation provided from all the three major pillars of rehabilitation i.e. physiotherapists, occupational therapists and prosthetics & orthotics that deal with artificial limbs, orthosis and assistive devices. As identified in a earlier study physiotherapists are the major key to the rehabilitation process [27] but the scenario are different in developing countries like India where trained and skilled physiotherapists are scarce & physiotherapy services are not present in rural areas. There is also a major barrier that prevent individuals with Spinal cord injury to receive proper rehabilitation- financial crisis as in developing countries rehab services are not covered under insurance neither government has policies that can provide either a good infrastructure or financial support to these individuals. Occupational therapists are known for training hand functions and improving one's quality of life. In country like India, even the colleges that teach occupational therapy and prosthetics & orthotics are few, how will the upcoming OTs and P&Os provide services to the entire population. Since there are fewer specialized SCI rehab centres available in India, the patient to therapist ratio will certainly be found to be high leading to less individualized attention on patients individualized goals and circumferential empowerment. So we might find less or no attention on vocational rehabilitation of an individual with Spinal cord injury. Through this study we may also find certain facilitators in empowering the individuals with Spinal cord injury like family & peer support, proper education availability, trained staff etc

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APPENDICES

Plagiarism Report

URKUND

Urkund Analysis Result

Analysed Document:	Akanksha_PhD Synopsis_24_8.docx (D111644209)
Submitted:	8/24/2021 7:48:00 PM
Submitted By:	asirjohnsamuel@mmumullana.org
Significance:	3 %

Sources included in the report:

http://www.rehabcouncil.nic.in/writereaddata/spinal.pdf
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Informed consent form (ICF)

This Informed Consent Form is for individuals who will attend the research project conducted at MMIPR, The title of our research project is “Experience of physical and vocational rehabilitation amongst individuals with paraplegia”

Name of Principal Investigator: Akanksha Saxena

Name of the Supervisor: Dr. Asir John Samuel

Name of Co-supervisor: Dr. Manjeet Singh

Name of Organization: MMIPR.

Name of Sponsor: Nil.

This Informed Consent Form has two parts:

- Information Sheet (to share information about the research with you)
- Certificate of Consent (for signatures if you agree to take part)

You will be given a copy of the full Informed Consent Form.

Part I: Information Sheet

Introduction

I am Akanksha Saxena, a student of Doctor of Philosophy (Physiotherapy) from MMIPR. I am doing a research to explore the experience of physical and vocational rehabilitation amongst the individuals with paraplegia. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them from me or another researcher.

Purpose of the research

Traumatic Spinal cord injury is a devastating condition that leaves a healthy individual paralyzed with an incidence of 20 per million per year population in India. Although attention is paid on the objective/ quantitative assessment, qualitative/ subjective assessment of rehabilitation still remains untouched. Till date, there is only one qualitative study regarding care of SCI in India. We want to learn first hand experience of rehabilitation be it physical (PT, OT & PO) care or vocational or employment opportunities being provided to you. We want to gather experience from individuals like you who have experienced rehabilitation in India and want to learn about the facilitators or barriers/ hindrances which individuals with paraplegia experience during their

rehabilitation phase, so that amendments in the rehabilitation protocol can be made. This knowledge provided by you will help us to provide the ground for improvements in rehabilitation process in future in India.

Type of Research Intervention

This research will involve your participation in a face to face interview that will take about forty-five minute to one hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience with rehabilitation can contribute much to our understanding and knowledge of the barriers & facilitators of the rehabilitation process.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at this Centre will continue and nothing will change.

Procedures

We are asking you to help us learn more about the rehabilitation experience in your community. We are inviting you to take part in this research project. If you accept, you will be asked about the probable facilitators, barriers or hindrances you experience during your rehabilitation process be it physical or vocational.

You will participate in a face to face interview with me.

During the interview, I will sit down with you in a comfortable place at the Centre. If it is better for you, the interview can take place in your home or a friend's home. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except me or Dr. Asir John Samuel will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The information recorded is confidential, and no one else except myself or Dr. Asir John Samuel will have access to the tapes.

Duration

This study requires to interview participants for only once and will take 30-45 minutes of your time.

Risks

There is no potential risk for participation in this study. However, there may be a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. Although we do not wish for this to happen. You do not have to answer any question in the interview if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about the experience of rehabilitation.

Reimbursements

You will not be provided any incentive to take part in the research. We cannot be able to pay you for your travelling and participation because our project is not funded.

Confidentiality

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Identity concealment is not totally guaranteed as the tapes and videos might be shared with the publication agency. Although your face will be hidden but your voice might be recognised. Any information about you will have a number on it instead of your name and only the researchers will know about that number. It will not be shared with or given to anyone except the other two researchers- Dr. Asir John Samuel & Dr. Manjeet Singh.

Sharing the Results

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public. Each participant will receive a summary of the results. There will also be

small meetings in the community and these will be announced. Following the meetings, we will publish the results so that other interested people may learn from the research.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your rehabilitation in our institute in any way. You may stop participating in the interview at any time that you wish. I will give you an opportunity at the end of the interview and for member checking too after I have summarized the results of your interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly

Who to Contact

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Dr. Akanksha Saxena(PT), 9958729161, akankshasaxena623@mmumullana.org

This proposal has been reviewed and approved by Institutional ethical committee of MMIMSR, which is a committee whose task it is to make sure that research participants are protected from harm.

Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction. I consent voluntarily to participate as a participant in this research.

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ AND Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

सूचित सहमति फॉर्म *(आईसीएफ)*

यह सूचित सहमति फॉर्म उन व्यक्तियों के लिए है जो एमएमआईपीआर में आयोजित शोध परियोजना में भाग लेंगे, हमारी शोध परियोजना का शीर्षक है "पैराप्लेजिया वाले व्यक्तियों के बीच शारीरिक और व्यावसायिक पुनर्वास का अनुभव"

प्रधान अन्वेषक का नाम*:* आकांक्षा सक्सेना

पर्यवेक्षक का नाम: डॉ. असीर जॉन सैमुअल

सह-पर्यवेक्षक का नाम: डॉ मंजीत सिंह

संगठन का नाम*:* एमएमआईपीआर।

प्रायोजक का नाम*:* शून्य।

इस सूचित सहमति फॉर्म के दो भाग हैं*:*

- सूचना पत्रक *(*आपके साथ शोध के बारे में जानकारी साझा करने के लिए*)*
- सहमति का प्रमाण पत्र *(*हस्ताक्षर के लिए यदि आप भाग लेने के लिए सहमत हैं*)*

आपको पूर्ण सूचित सहमति फॉर्म की एक प्रति दी जाएगी।

भाग *I:* सूचना पत्र

परिचय

मैं आकांक्षा सक्सेना, एमएमआईपीआर से डॉक्टर ऑफ फिलॉसफी (फिजियोथेरेपी) की छात्रा हूं। मैं पक्षाघात से पीड़ित व्यक्तियों के बीच शारीरिक और व्यावसायिक पुनर्वास के अनुभव का पता लगाने के लिए एक शोध कर रहा हूं। मैं आपको जानकारी देने जा रहा हूं और आपको इस शोध का हिस्सा बनने के लिए आमंत्रित करता हूं। आपको आज यह तय करने की आवश्यकता नहीं है कि आप शोध में भाग लेंगे या नहीं। निर्णय लेने से पहले, आप अनुसंधान के बारे में किसी ऐसे व्यक्ति से बात कर सकते हैं जिसके साथ आप सहज महसूस करते हैं।

इस सहमति फॉर्म में ऐसे शब्द हो सकते हैं जिन्हें आप नहीं समझते हैं। कृपया मुझे रुकने के लिए कहें क्योंकि हम जानकारी के माध्यम से जाते हैं और मुझे समझाने में समय लगेगा। यदि बाद में आपके कोई प्रश्न हों, तो आप मुझसे या किसी अन्य शोधकर्ता से पूछ सकते हैं।

शोध का उद्देश्य

दर्दनाक रीढ़ की हड्डी की चोट एक विनाशकारी स्थिति है जो भारत में प्रति वर्ष 20 प्रति मिलियन की आबादी के साथ एक स्वस्थ व्यक्ति को पंगु बना देती है। यद्यपि उद्देश्य/मात्रात्मक मूल्यांकन पर ध्यान दिया जाता है, फिर भी पुनर्वास का गुणात्मक/व्यक्तिपरक मूल्यांकन अभी भी अछूता है। आज तक, भारत में एससीआई की देखभाल के संबंध में केवल एक गुणात्मक अध्ययन है। हम पुनर्वास का प्रत्यक्ष अनुभव सीखना चाहते हैं, चाहे वह शारीरिक (पीटी, ओटी और पीओ) देखभाल हो या व्यावसायिक या रोजगार के अवसर जो आपको प्रदान किए जा रहे हों। हम आप

जैसे व्यक्तियों से अनुभव प्राप्त करना चाहते हैं, जिन्होंने भारत में पुनर्वास का अनुभव किया है और उन सुविधाकर्ताओं या बाधाओं/बाधाओं के बारे में जानना चाहते हैं, जिन्हें उनके पुनर्वास चरण के दौरान पक्षाघात से पीड़ित व्यक्ति अनुभव करते हैं, ताकि पुनर्वास प्रोटोकॉल में संशोधन किया जा सके।

अनुसंधान हस्तक्षेप का प्रकार

इस शोध में आमने-सामने साक्षात्कार में आपकी भागीदारी शामिल होगी जिसमें लगभग पैंतालीस मिनट से एक घंटे तक का समय लगेगा।

प्रतिभागी चयन

आपको इस शोध में भाग लेने के लिए आमंत्रित किया जा रहा है क्योंकि हमें लगता है कि पुनर्वास के साथ आपका अनुभव पुनर्वास प्रक्रिया की बाधाओं और सुगमकर्ताओं के बारे में हमारी समझ और ज्ञान में बहुत योगदान दे सकता है।

स्वैच्छिक भागीदारी

इस शोध में आपकी भागीदारी पूर्णतः स्वैच्छिक है। यह आपकी मर्जी है कि भाग लेना है या नहीं। यदि आप इस केंद्र में प्राप्त होने वाली सभी सेवाओं में भाग नहीं लेना चुनते हैं तो यह जारी रहेगा और कुछ भी नहीं बदलेगा।

प्रक्रियाओं

हम आपसे आपके समुदाय में पुनर्वास के अनुभव के बारे में अधिक जानने में हमारी सहायता करने के लिए कह रहे हैं। हम आपको इस शोध परियोजना में भाग लेने के लिए आमंत्रित कर रहे हैं। यदि आप स्वीकार करते हैं, तो आपसे संभावित सहायकों, बाधाओं या आपकी पुनर्वास प्रक्रिया के दौरान आपके द्वारा अनुभव की जाने वाली बाधाओं के बारे में पूछा जाएगा, चाहे वह शारीरिक या व्यावसायिक हो।

आप मेरे साथ आमने-सामने साक्षात्कार में भाग लेंगे।

साक्षात्कार के दौरान, मैं आपके साथ केंद्र में एक आरामदायक जगह पर बैठूंगा। अगर आपके लिए बेहतर है तो इंटरव्यू आपके घर या किसी दोस्त के घर में हो सकता है। यदि आप साक्षात्कार के दौरान किसी भी प्रश्न का उत्तर नहीं देना चाहते हैं, तो आप ऐसा कह सकते हैं और साक्षात्कारकर्ता अगले प्रश्न पर चला जाएगा। साक्षात्कारकर्ता के अलावा और कोई नहीं होगा जब तक कि आप नहीं चाहेंगे कि कोई और वहां मौजूद रहे। दर्ज की गई जानकारी गोपनीय है, और मेरे या डॉ॰ असीर जॉन सैमुअल को छोड़कर किसी और के पास आपके साक्षात्कार के दौरान प्रलेखित जानकारी तक पहुंच नहीं होगी। पूरे इंटरव्यू की टेप-रिकॉर्डिंग की जाएगी, लेकिन टेप पर नाम से किसी की पहचान नहीं होगी। दर्ज की गई जानकारी गोपनीय है, और मेरे या डॉ॰ असीर जॉन सैमुअल को छोड़कर किसी और के पास टेप तक पहुंच नहीं होगी।

अवधि

इस अध्ययन के लिए प्रतिभागियों का केवल एक बार साक्षात्कार करना आवश्यक है और इसमें आपका *30-45* मिनट का समय लगेगा।

जोखिम

इस अध्ययन में भाग लेने का कोई संभावित जोखिम नहीं है। हालाँकि, यह जोखिम हो सकता है कि आप संयोग से कुछ व्यक्तिगत या गोपनीय जानकारी साझा कर सकते हैं, या कि आप कुछ विषयों के बारे में बात करने में असहज महसूस कर सकते हैं। हालांकि हम नहीं चाहते कि ऐसा हो। यदि आपको लगता है कि प्रश्न बहुत व्यक्तिगत हैं या यदि उनके बारे में बात करना आपको असहज करता है तो आपको साक्षात्कार में किसी भी प्रश्न का उत्तर देने की आवश्यकता नहीं है।

लाभ

आपको कोई प्रत्यक्ष लाभ नहीं होगा, लेकिन आपकी भागीदारी से हमें पुनर्वास के अनुभव के बारे में अधिक जानने में मदद मिलने की संभावना है।

पैसे की वापसी

आपको शोध में भाग लेने के लिए कोई प्रोत्साहन प्रदान नहीं किया जाएगा। हम आपकी यात्रा और भागीदारी के लिए आपको भुगतान करने में सक्षम नहीं हो सकते क्योंकि हमारी परियोजना को वित्त पोषित नहीं किया गया है।

गोपनीयता

समुदाय में किया जा रहा शोध ध्यान आकर्षित कर सकता है और यदि आप भाग लेते हैं तो समुदाय के अन्य लोगों द्वारा आपसे प्रश्न पूछे जा सकते हैं। हम आपके बारे में शोध दल के बाहर किसी को भी जानकारी साझा नहीं करेंगे। हम इस शोध परियोजना से जो जानकारी एकत्र करते हैं उसे निजी रखा जाएगा। पहचान छुपाने की पूरी गारंटी नहीं है क्योंकि टेप और वीडियो प्रकाशन एजेंसी के साथ साझा किए जा सकते हैं। हालांकि आपका चेहरा छिपा रहेगा लेकिन आपकी आवाज पहचानी जा सकती है। आपके बारे में किसी भी जानकारी पर आपके नाम के बजाय एक नंबर होगा और उस नंबर के बारे में केवल शोधकर्ताओं को ही पता चलेगा। इसे अन्य दो शोधकर्ताओं- डॉ॰ असीर जॉन सैमुअल और डॉ चित्रा कटारिया को छोड़कर किसी के साथ साझा या दिया नहीं जाएगा।

परिणाम साझा करना

आज आप हमें जो कुछ भी बताएंगे, वह शोध दल के बाहर किसी के साथ साझा नहीं किया जाएगा, और आपके नाम से कुछ भी नहीं जोड़ा जाएगा। इस शोध से हमें जो ज्ञान मिलता है, उसे जनता के लिए व्यापक रूप से उपलब्ध कराने से पहले आपके और आपके समुदाय के साथ साझा किया जाएगा। प्रत्येक प्रतिभागी को परिणामों का सारांश प्राप्त होगा। समुदाय में छोटी-छोटी बैठकें भी होंगी और इनकी घोषणा की जाएगी। बैठकों के बाद, हम परिणाम प्रकाशित करेंगे ताकि अन्य इच्छुक लोग शोध से सीख सकें।

मना करने या वापस लेने का अधिकार

यदि आप ऐसा नहीं करना चाहते हैं तो आपको इस शोध में भाग लेने की आवश्यकता नहीं है, और भाग लेने का चुनाव हमारे संस्थान में आपके पुनर्वास को किसी भी तरह से प्रभावित नहीं करेगा। आप अपनी इच्छानुसार किसी भी समय साक्षात्कार में भाग लेना बंद कर सकते हैं। आपकी टिप्पणियों की समीक्षा करने के लिए आपके साक्षात्कार के परिणामों को संक्षेप में प्रस्तुत करने के बाद, मैं आपको साक्षात्कार के अंत में और सदस्य जाँच के लिए एक अवसर दूंगा, और यदि आप मेरी टिप्पणियों से सहमत नहीं हैं, तो आप उनमें से कुछ को संशोधित करने या हटाने के लिए कह सकते हैं। नोट्स या अगर मैं आपको सही ढंग से समझ नहीं पाया

किससे संपर्क करें

यदि आपके कोई प्रश्न हैं, तो आप उन्हें अभी या बाद में पूछ सकते हैं। यदि आप बाद में प्रश्न पूछना चाहते हैं, तो आप निम्न में से किसी से भी संपर्क कर सकते हैं:

डॉ॰ आकांक्षा सक्सेना, *9958729161, akankshasaxena623@mmumullana·org*

इस प्रस्ताव की समीक्षा की गई है और एमएमआईएमएसआर की संस्थागत नैतिक समिति द्वारा अनुमोदित किया गया है, जो एक समिति है जिसका कार्य यह सुनिश्चित करना है कि शोध प्रतिभागियों को नुकसान से बचाया जाए।

सहमति का प्रमाण पत्र

मैंने पूर्वगामी जानकारी पढ़ ली है, या यह मुझे पढ़ ली गई है। मुझे इसके बारे में प्रश्न पूछने का अवसर मिला है और मेरे द्वारा पूछे गए किसी भी प्रश्न का उत्तर मेरी संतुष्टि के अनुरूप दिया गया है। मैं स्वेच्छा से इस शोध में भागीदार के रूप में भाग लेने के लिए सहमत हूं।

प्रतिभागी का प्रिंट नाम _____

प्रतिभागी के हस्ताक्षर _____

दिनांक _____

दिन महीने साल

अगर अनपढ़

मैंने संभावित सहभागी को सहमति प्रपत्र का सटीक पठन देखा है, और व्यक्ति को प्रश्न पूछने का अवसर मिला है। मैं पुष्टि करता हूं कि व्यक्ति ने स्वतंत्र रूप से सहमति दी है।

गवाह का नाम _____ और प्रतिभागी का अंगूठा प्रिंट

गवाह के हस्ताक्षर _____

दिनांक _____

दिन महीने साल

Demographic details form

- Name
- Age
- Gender
- Marital status
- Time since injury
- Cause of injury
- Level of injury
- ASIA impairment grade
- Educational level
- Pre-SCI job type
- Current employment status

Interview Guide with Content Validation Scores

SR. NO	QUESTIONS	I-CVI
	General experience & expectations from rehabilitation care	
1.	How would you describe your overall time at the: • Inpatient/ICU unit Probes: for example-food, hygiene, nutrition etc. Can you give an example of that • Outpatient care/ OPD care unit after SCI Probes: for example-was it good, bad or both? Why do you think that was. Can you explain it in detail.	0.78
2.	Can you tell me what kind of rehabilitation you receive and what your experience with them is: Probes: Which healthcare professionals are on your team?	0.78
3.	How do these professional decide/ make your exercise protocol? Can you think of an example when you were involved in decision making of protocol & timings? Probes: What happened? Who involved you & how did it make you feel? Do you think it worked well in your case?	1
4.	Describe about your experience with usage of assistive devices. Probes: Who provided it and was it cost-effective & sufficient enough in everyday life.	0.89
5.	Over the years, have you noticed any change in the behavior of your attendants or family members? Probes: How has the support & social interaction changed? Can you describe any positive or negative changes in your relationship with them.	0.89
	Physical rehabilitation experience/ barriers/facilitators	
6.	How has the rehabilitation helped you in: a. Your ADL's or day to day activities of self-care b. Transfers c. Bed-mobility d. Prevention of complications	0.89

	e. Mobility/capacity to move around	
7.	Describe how physiotherapy/rehabilitation helped in your community integration? Probes: for example in moving around, socializing, travelling etc. Were the exercises realistic or applicable in real life?	1
8.	What do you think are the barriers you are encountering in your rehabilitation? Probes: for example-staff issues, improper care, architectural barriers, transportation, finances etc.	0.89
9.	Similarly, what are the facilitators you are encountering in your rehabilitation?	0.89
10.	Tell about your awareness about the government policies, insurance or financial benefits you receive or can receive for your rehabilitation? Probes: what about the access to these facilities? Were there any challenges. Please describe them.	0.89
11.	Provide us some feedback regarding your rehabilitation? Probes: Tell me about your unmet expectations. Can you describe differences in realistic and expected outcomes.	0.89
Vocational rehabilitation		
12.	How has SCI changed your work life or education life? Probes: Describe the positive & negative changes.	0.89
13.	What kind of support are you being provided for future employment? Probes: Pension, employment compensation, vocational training etc.	0.89
14.	In your opinion, what are the obstacles in returning to work?	0.89
15.	What are your views on current rehabilitation scenario in India? Give suggestions in improving rehabilitation for individuals with SCI.	1